

European Federation of Allergy and Airways Diseases Patients' Associations

# EFA Annual Report 2011



## European Federation of Allergy and Airways Diseases Patients' Associations 2011 Annual Report

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## INTRODUCTION

### Foreword

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*EFA is 20 Years old!*



Our journey was celebrated with members, honorary members and past presidents at our Annual Meeting in May, those who served EFA and those EFA is composed of and who it serves. Looking back with some nostalgia but never regrets. Today we are recognized and visible stakeholder at the European level, and have been able to expand our activities to serve the interest of people with allergy, asthma and COPD in Europe. It is impossible to estimate how many volunteer hours let alone how much commitment it has taken over the years to arrive where we are now. Each and everyone who have contributed to EFA over the years, whether with funding, brilliance, dedication, commitment and pure and simple hard work were remembered and celebrated this year.

As if it was planned, our celebration year coincided with the **EU Polish presidency priority on children's respiratory diseases** – the first time that our disease areas received high level attention at the EU level and patients were given a visible role. This was particularly timely, as EFA run two high level projects this year on allergy and COPD.

In December, this priority culminated in **European Council Conclusions on Prevention, Early Diagnosis and Treatment Respiratory Diseases in Children**<sup>1</sup>, an important political document that we can build on, and a success to celebrate.

This report gives an overview of our main actions this year. In addition EFA was very involved in the work of the European Medicines Agency, co-authored several publications, was represented either as a speaker or participant in more than 50 events related to EU policy or to partnership with health care professional associations or other NGOs. I hope you enjoy reading it.

Thank you to all EFA members, supporting EU policy makers at the Parliament, Commission and the Council, partners and funding partners,

*Breda Flood*

EFA President

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<sup>1</sup> [http://www.consilium.europa.eu/uedocs/cms\\_Data/docs/pressdata/en/lsa/126522.pdf](http://www.consilium.europa.eu/uedocs/cms_Data/docs/pressdata/en/lsa/126522.pdf)



Patients at the EU Polish Presidency Conference 21-22 of September in Warsaw, '[Prevention and control of childhood asthma and allergy in the EU from the public health point of view: urgent need to fill the gaps](#)'

## About EFA

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EFA is a European network of patient organizations that was founded in 1991, prompted by the belief that an international organization formed by European patients associations that share the same aims would be a more effective way to serve the needs and safeguard the rights of patients and their carers.

EFA was created to combine the forces of national patient associations on asthma and allergy for results at European level and to improve the health and quality of life of people in Europe with those diseases. Serving the interests of allergy and airways patients at the national level is the primary responsibility of individual members and EFA supports member organisations by facilitating the sharing of knowledge and experiences.

### Vision

EFA is the leading reference point for people with allergy, asthma and COPD.

EFA is dedicated to making Europe a place where:

- People with allergy, asthma and COPD have the right to best quality of care and safe environment
- People with allergy, asthma and COPD live uncompromised lives.
- People with allergy, asthma and COPD are actively involved in all decisions influencing their health

### Mission

EFA is aiming to be a powerful European Network of allergy, asthma and COPD patients organizations that:

- Advocates at EU level the needs of people with Allergy, asthma and COPD
- Values all members equally
- Implements best practice
- Creates patient driven projects

- Cooperates with health care professionals, scientists and other stakeholders/NGOs

### **Objectives by target audience**

- For member organizations
  - Actively communicates with member organizations identifying their needs
  - Develops projects to meet these needs.
- For Patients
  - Provides transparent access to information and educational tools in patient-friendly language
  - Provides opportunities to participate actively in projects.
- For Healthcare Professionals/Scientists
  - Facilitates communication in patient-friendly language focusing on patient needs
  - Develops and promotes long term partnership on equal level
  - Ensures active participation of patients in all decisions regarding their disease
- For Policy makers
  - Acts as liaison between people with allergy, asthma and COPD and EU policy-makers
  - Negotiates to raise standards of care, environment and research
  - Communicates and updates about patient needs
- For NGOs and Industry
  - Develops and promotes long term partnership
  - Ensures well defined conditions of partnership

### **Central Values**

- Patient perspective
- Involvement
- Sharing knowledge and experience
- Partnership and cooperation  
Visibility and presence

# 1 ORGANISATION

## Board

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### **Until 6 May 2011**

#### *President*

Marianella Salapatas

ANIKSI, Greece

Email: [msalapatas@gmail.com](mailto:msalapatas@gmail.com)

#### *Vice President*

Christine Rolland

Association Asthme&Allergies, France

Email: [ch.rolland@asthme-allergies.asso.fr](mailto:ch.rolland@asthme-allergies.asso.fr)

#### *Treasurer*

Breda Flood

Asthma Society of Ireland

Email: [breda.flood@efanet.org](mailto:breda.flood@efanet.org)

#### *Board Secretary*

Per-Åke Wecksell

Swedish Asthma and Allergy Association

Email: [per-ake.ecksell@astmaoallergiforbundet.se](mailto:per-ake.ecksell@astmaoallergiforbundet.se)

#### *Member-at-Large*

Lina Buzermaniene

Lithuanian Council of Asthma Clubs

Email: [lina.buzermaniene@efanet.org](mailto:lina.buzermaniene@efanet.org)

### **From 7 May 2011**

#### *President*

Breda Flood

Asthma Society of Ireland

Email: [breda.flood@efanet.org](mailto:breda.flood@efanet.org)

#### *Vice President*

Christine Rolland

Association Asthme&Allergies, France

Email: [ch.rolland@asthme-allergies.asso.fr](mailto:ch.rolland@asthme-allergies.asso.fr)

#### *Treasurer*

Ondrej Rybnicek

Czech Initiative for Asthma (CIPA)

Email [Rybnicek.O@seznam.cz](mailto:Rybnicek.O@seznam.cz)

#### *Board Secretary*

Per-Åke Wecksell

Swedish Asthma and Allergy Association

Email: [wecksell@hotmail.com](mailto:wecksell@hotmail.com)

*Member-at-Large*

Lina Buzermaniene

Lithuanian Council of Asthma Clubs

Email: [lina.buzermaniene@efanet.org](mailto:lina.buzermaniene@efanet.org)

## Office

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The EFA Office was located at 35 Rue du Congrès

1000 Brussels, Belgium

Tel. +32 (0)2 227 2712

Fax. +32 (0)2 218 3141

*Executive Officer*

Susanna Palkonen

Email: [susanna.palkonen@efanet.org](mailto:susanna.palkonen@efanet.org)

*Project and Fundraising Officer*

Antje Fink-Wagner

Email: [antje.finkwagner@efanet.org](mailto:antje.finkwagner@efanet.org)

*EU Policy and Project Assistant (until 28 February)*

*EFA ezine Editor (from 1 March)*

Patricia Murray

*EU Policy and Project Assistant (from 1 November)*

David Brennan

Email: [info@efanet.org](mailto:info@efanet.org)

*EU Policy and Project Officer (from 1 December)*

Roberta Savli [roberta.savli@efanet.org](mailto:roberta.savli@efanet.org)

## Members

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The EFA membership 2011 consists of 33 allergy, asthma and/or COPD patient associations or their coalitions in 21 European countries, in which there are over 500.000 individual patients and carers as members. EFA represents its member associations on a European level, whereas the associations represent their individual members in their respective countries.

*Austria*

Österreichische LungenUnion (ÖLU) [www.lungenunion.at](http://www.lungenunion.at)

*Belgium*

Coalition of Prevention des Allergies asbl [www.oasis-allergies.org](http://www.oasis-allergies.org)

Astma-en Allergiekoepel v.z.w. [www.astma-en-allergiekoepel.be](http://www.astma-en-allergiekoepel.be)

Fondation contre les affections respiratoires et pour l'éducation à la santé (F.A.R.E.S.) [www.fares.be](http://www.fares.be)

*Bulgaria*

Association of Bulgarians with Bronchial Asthma (ABBA) [www.asthma-bg.com](http://www.asthma-bg.com)

*Czech Republic*

Czech Initiative for Asthma [www.cipa.cz](http://www.cipa.cz)

*Denmark*

Astma-Allergi Forbundet [www.astma-allergi.dk](http://www.astma-allergi.dk)

*Finland*

Allergia-ja Astmaliitto - Allergy and Asthma Federation [www.allergia.com](http://www.allergia.com)

Hengitysliitto Heli – Pulmonary Association Heli [www.hengitysliitto.fi](http://www.hengitysliitto.fi)

*France*

Association Asthme & Allergies [www.asmanet.com](http://www.asmanet.com)

Coalition of Association Française pour la Prévention des Allergies (AFPRAL) [www.prevention-allergies.asso.fr](http://www.prevention-allergies.asso.fr)

Fédération Française des Associations et Amicales d'Insuffisants Respiratoires (FFAAIR) [www.ffaair.org](http://www.ffaair.org)

*Germany*

Patientenliga Atemwegserkrankungen e.V. [www.patientenliga-atemwegserkrankungen.de](http://www.patientenliga-atemwegserkrankungen.de)

*Greece*

ANIKSI [www.allergyped.gr](http://www.allergyped.gr)

*Ireland*

Asthma Society of Ireland [www.asthmasociety.ie](http://www.asthmasociety.ie)

*Italy*

Coalition of FEDERASMA [www.federasma.org](http://www.federasma.org)

Associazione Italiana Pazienti BPCO (AIPBPCO) [www.pazientibpco.it](http://www.pazientibpco.it)

*Lithuania*

Coalition of Association of Allergic Children Clubs and Association of Asthma Patient Clubs

Lithuanian Council of Asthma Clubs [www.astmainfo.lt](http://www.astmainfo.lt)

*Luxembourg*

Satellite of Prevention des Allergies asbl, Belgium

*Netherlands*

Nederlands Astma Fonds (AF) [www.astmafonds.nl](http://www.astmafonds.nl)

Coalition of Stichting Voedsel Allergie - Dutch Food Allergy Organisation [www.stichtingvoedselallergie.nl](http://www.stichtingvoedselallergie.nl)

Vereniging voor Mensen met Constitutioneel Eczeem (VMCE) [www.vmce.nl](http://www.vmce.nl)

*Norway*

Norges Astma- og Allergiforbund (NAAF - Norwegian Asthma and Allergy Association) [www.naaf.no](http://www.naaf.no)



*Poland*

Polish Federation of Asthma, Allergy and COPD Patients' Organisations [www.astma-alergia-pochp.pl](http://www.astma-alergia-pochp.pl)

*Portugal*

Portuguese Asthma Patients Association APA [www.apa.pt](http://www.apa.pt)

*Slovenia*

Pulmonary and Allergy Patients' Association of Slovenia (DPBS) [www.astma-info.com](http://www.astma-info.com)

*Sweden*

Astma- och Allergiförbundet - Swedish Asthma and Allergy Association

[www.astmaoallergiforbundet.se](http://www.astmaoallergiforbundet.se)

Swedish Heart and Lung Association [www.hjart-lung.se](http://www.hjart-lung.se)

*Switzerland*

Coalition of aha! Schweizerisches Zentrum für Allergie, Haut und Asthma [www.ahaswiss.ch](http://www.ahaswiss.ch)

Lungeliga Schweiz - Swiss Lung Association [www.lung.ch](http://www.lung.ch)

*U.K.*

Allergy UK [www.allergyuk.org](http://www.allergyuk.org)

**Honorary members**

Edith M.A.L. Rameckers, the Netherlands

Erkka Valovirta, Finland

Elizabeth Bell, U.K.

Arne Heimdal, Norway

**Project members**

*Board lead for MeDALL Project*

*Board liaison for the GA<sup>2</sup>P<sup>2</sup> project*

Per-Åke Wecksell, Sweden

*Board lead for the U-BIOPRED Project*

Breda Flood, Ireland

*Board lead for HealthVent Project*

Christine Rolland

*Medical Advisor & Editor of EFA Book on Respiratory Allergy*

Erkka Valovirta, Finland

*European Medicines Agency (EMA) Patient experts*

Lina Buzermaniene, Lithuania

Breda Flood, Ireland

Marianella Salapatias, Greece

Ondrej Rybnicek, Czech Republic

Per-Ake Wecksell, Sweden

*COPD Patient Advisor to the Board*

Michael Wilken, Patientenliga Atemwegserkrankungen, Germany

*Allergy Patient Advisor at EFA Allergy Project*

Joanna Bottema, Netherlands Asthma Fonds

### **Working groups**

*COPD*, chair Michael Wilken, Patientenliga Atemwegserkrankungen, Germany

*Severe asthma*

*Allergy*, chair Christine Rolland

*Food allergy*

*Members Steering Group*, chair Per-Åke Wecksell

Members : Christine Rolland, Asthme&Allergies, France

Liliya Gentet, FFAAIR

Lina Buzermaniene, Lithuanian Council of Asthma Clubs

Luigi Visintin, FEDERASMA

Muriel Simmons, Allergy UK

## **Memberships and Representation**

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*European Patients Forum (EPF)*

Susanna Palkonen, Vice President

*European Network for Smoking Prevention (ENSP)*

*Health and Environment Alliance (HEAL)*

*Global Alliance against Respiratory Diseases (GARD)*, Otto Spranger, Austria, Member of the Planning Group

*International COPD Coalition (ICC)*

*DG Environment Consultative Forum on Environment and Health*: representative Susanna Palkonen

*DG SANCO Expert Group on Indoor Air Quality*

Susanna Palkonen, Member

*European Medicines Agency Patient and Consumer Working Party*, representative Lina

Buzermaniene, alternate Breda Flood

*Advisory Group of the Integrated Exposure for Risk Assessment in indoor environments (INTERA) project*

*Advisory Group of the Schools Indoor Pollution and Health Observatory Network SINPHONIE project from EU Public Health Programme <http://www.sinphonie.eu/>*

*Allergic Rhinitis and Its Impact on Asthma (ARIA) Advisory Committee*

*Editorial Board of the Italian Journal of Primary Care*

*European Medicines Agency Patient and Consumer Working Party on behalf of the EPF*

*User Advisory Board of the [Renewing Health project](#) from the EC ICT Policy Support Programme*

*GSK European Health Advisory Board*  
Susanna Palkonen, Member

*Scientific Committee of the EU Polish Presidency Conference on Children's respiratory Diseases*  
Breda Flood & Susanna Palkonen, Members

*EAACI Task force on Primary Care*  
Christine Rolland, Member

*European Lung Foundation Executive Committee*  
*EAACI Patient Organisation Committee*  
*Steering Group of the European Commission Ex Smokers are Unstoppable Campaign*  
*AIRPROM project Exploitation Committee*  
Breda Flood, Member

*Global Allergy and Asthma Patient Platform GA<sup>2</sup>P<sup>2</sup> Board*  
Per-Ake Wecksell, Member

*International Primary Care Respiratory Group (IPCRG)*  
Associate Member

## Strategic Priorities 2011

The EFA 'niche' is being the only European level patient organisation for people with allergy, asthma and COPD, who are represented through EFA member organisations. To make EFA a powerful organisation at the service of patients and members, EFA will:

- Advocate at EU level the needs of people with allergy, asthma and COPD
- Work more and equally with members
- Implement best practice
- Create patient driven projects
- Cooperate with health care professionals, scientists and other stakeholders/NGOs

The work priorities for 2011 are:

- High quality EFA owned projects patient at the core: COPD Project, Allergy project & contribution to our EU advocacy
- EU project partnerships: delivering in U-BIOPRED, MeDALL, AIRProm, HealthVent
- EU policy
- Staff: capacity through recruitment of EU Policy & Project Officer
- Funding: development, growth, diversity
- New website as EFA ambassador and effective interactive information and advocacy tool

## 2 MAIN ACTIVITIES

### Governance

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#### AGM

The Annual General Meeting (AGM) was held 6 May in Paris, France. Our external auditor audited the accounts for the approval of the AGM 2011 as usual. During the AGM many important issues were discussed. During this year's elections the president and two board members were elected to [the Board](#). EFA welcomes its new President Breda Flood from the Asthma Society of Ireland and welcomed back Per-Åke Wecksell from Swedish Asthma and Allergy Association and Ondrej Rybnicek from the Czech Initiative Asthma. Marianella Salapatas was warmly thanked of her great contribution to EFA, as she now stood down from EFA presidency having served the full three terms in the board.



The EFA board met 3 times in Brussels, one meeting was a combined strategic and regular meeting and one in Barcelona in connection of an EU project meeting. In addition the board had regular meetings via skype to stay on top of the regular business and leave time in face-to-face meetings for key board issues.

The AGM decided on EFA short term strategy and work plan and implemented a new membership fee structure for 2012, 500 euros/member, instead of the current 1500/member or coalition of members in a given country. This should in the future enable more organisations to join, even small ones and not force into purpose made coalitions towards EFA given that EFA represents several disease areas. In addition, the Members Steering Group presented outcomes of their work and emphasized communication, member involvement and need for opportunities collaborate and have dialogue with colleagues. These principles should be integrated as a red line in all EFA planning. In particular, EFA needs a new interactive website, and the planning for this was started. EFA also covered expenses of one delegate per member association to join the AGM and Network meeting.

#### Network Meeting

Based on the feedback by members and for the first time EFA held a Networking Meeting<sup>2</sup> of Members the day following the AGM. The entire day was devoted for sharing and discussing best practices on projects, policies and practices at national level and EFA disease specific working groups

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<sup>2</sup> <http://www.efanet.org/activities/EFANetworkMeetingDraftProgramme.docx>

among colleagues from fellow associations across Europe in an informal way. Interesting presentations were given by several member organisations, and included such diverse topics as patient participation in research in Sweden, allergy education in Czech schools, and a national allergy programme in Finland. It was clear that EFA needs to develop the networking concept further for next year.

## **Office**

EFA Office in Brussels has Executive Officer, part-time Project and Fundraising Officer and full-time EU Policy and Project Assistant and since the end of the year, full-time EU Policy and Project Officer. In addition, EFA has project members/leaders dealing with different projects and uses external services as appropriate. The rest of the work is voluntary, board members each having specific responsibilities, supported by the Office and members contributing on voluntary basis to our projects and coordinated EU advocacy.

## **Funding**

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In 2011, EFA funding was based on membership fees 6%, European Commission Project funding 11% and 53% core-funding and 30% project funding from our 10 sustainable corporate partners representing all our disease areas. EFA funding increased one third thanks to our ongoing outreach to potential partners and clear and transparent operation of our framework for partnership<sup>3</sup> based on trust. The partners are acknowledged at the end of this report.

The project funding from the Commission increased, EFA now being involved as partner in 4 projects both the Health Programme and the 7<sup>th</sup> Framework Programme for Research.

In connection of our AGM in May EFA had a special meeting for our sustainable funding partners in Brussels to present EFA work done 2010 and outlook for the 2011. All partners attended the meeting. New and old partners also had the opportunity comment on their experience in supporting EFA.

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<http://www.efanet.org/about/documents/FinalSustainableCorporatePartnershipArrangementsEFAJune09.doc>

### Respiratory Allergy Project



In 2011 EFA embarked on our four year 'EFA Allergy Awareness Project', an initiative to raise awareness of respiratory allergies as serious and chronic diseases. The aim is to highlight the need for action on respiratory allergy drawing attention of policy makers to the dramatic increase in allergies as 20%-30% of the world's population are affected by some form of allergic reaction. Respiratory allergies are the most common allergies both in Europe and worldwide and it is estimated that by 2015 1 in every 2 Europeans will suffer from an allergy. Despite this, awareness of the issue remains low and patients are often the first to ignore their condition.

A survey, similar style as our previous one on COPD was developed to map from EFA member associations issues such as training, access to prevention treatment, quality of healthcare and reimbursement policy, and current awareness of respiratory allergy. 18 countries took part in the survey. The results were summarized in EFA Book on Respiratory Allergies Raise Awareness, Relieve the Burden<sup>4</sup>. It revealed a wealth of information on the state of allergies across the EU, the urgent need for increased awareness of respiratory allergies, and highlights the loopholes and inequalities which are affecting many European patients.

On the 22 of November, the Book was launched<sup>5</sup> at the European Parliament in Brussels hosted by MEPs Elisabetta Gardini and Nessa Childers, including a **Call to Action for Europe**<sup>6</sup> asking **governments and the EU to**

- ✓ **recognise** allergy as a real and serious disease,
- ✓ **promote** national programmes to raise awareness,
- ✓ **prioritise** the prevention, management and control of allergy,
- ✓ **encourage** training of healthcare professionals,
- ✓ **adapt** healthcare and reimbursement policies for patients and
- ✓ **improve** air quality.

<sup>4</sup> <http://www.efanet.org/documents/EFABookonRespiratoryAllergiesFINAL.pdf>

<sup>5</sup>

[http://www.efanet.org/newsletter/lt/t\\_go.php?i=&e=%25subscriberid%25&l=http://www.efanet.org/documents/LaunchedofEFAAllergyProjectPressRelease.pdf](http://www.efanet.org/newsletter/lt/t_go.php?i=&e=%25subscriberid%25&l=http://www.efanet.org/documents/LaunchedofEFAAllergyProjectPressRelease.pdf)

<sup>6</sup> <http://www.efanet.org/documents/EFACalltoAction17Novembre.pdf>

Proactive allergy programmes which take the above into account will reduce the burden of the disease, financial and otherwise, on individuals and society. The successful event gathered MEPs, EU officials, representatives of the Polish Presidency of the EU and patient and medical representatives. For the next year EFA plans educational activities on national allergy plans for members, health care professionals and policy makers.



Alex, child with respiratory allergy and his Mother, EU Polish Presidency representative Boleslaw Samolinski, MEP Elisabetta Gardini & EFA's Susanna Palkonen

## COPD Project

After EFA's Call to Action on COPD in the European Parliament in 2010 and the successful launch of the EFA Book on COPD in Europe, 2011 was dedicated for a follow-up project that will develop together with EU policy makers, health care professionals, patients and other stakeholders the Call to Action through presentation of best practice into concrete action point and EU policy initiative.

### 1st EFA COPD workshop – Prevention and Early diagnosis

29 June EA held a successful expert workshop on COPD prevention and early diagnosis in the European Parliament in Brussels – attended by COPD patients and their representatives, medical experts, MEPs from the main European political parties and representatives from the European Commission. Speakers from our partner organisations for this project ERS and ELF provided some examples of best practice, such as the Danish experience on promoting early diagnosis and an employer representative shared their programme on supporting quitting smoking at the workplace. The participating COPD patients played a central role in the event. The results were published in the 1<sup>st</sup> EFA COPD Project Newsletter<sup>7</sup>. In addition to this, an article<sup>8</sup> written by workshop host MEP Seán Kelly drawing attention to the urgency of addressing COPD and creating awareness of the issue in the European Parliament was published in the European Parliament magazine in June ahead of the

<sup>7</sup> <http://www.efanet.org/documents/EFANewsletterCOPDWorkshop1.pdf>

<sup>8</sup> <http://www.efanet.org/enews/documents/ARTICLE.pdf>



workshop. The other three supporting MEPs were Eva Britt Svensson, Catherine Stihler and Françoise Grossetete.



#### Policy Recommendations – Prevention & Early Diagnosis of COPD

- ✓ **Prevention:** occupational and passive exposure to risk factors such as smoke needs to be further limited;
- ✓ **Smoking cessation:** with a view to promoting smoking cessation, healthcare professionals need to be remunerated for their efforts to help smokers fight their addiction and quit; good practice in employer-led health promotion programmes needs to be promoted and disseminated. Investments into health on behalf of the employer need to be encouraged, the economic benefits of a healthy workforce need to be flagged more strongly.
- ✓ **Tobacco labeling:** COPD needs to be mentioned explicitly as a debilitating and fatal lung disease on tobacco packaging, in order to raise awareness of the disease and give a warning to those who smoke.
- ✓ **Education of healthcare professionals:** co-operation between those working in primary care and specialists needs to be established with a view to a correct interpretation of lung function test results. Rigorous training needs to be given to those who do not have access to specialist knowledge.
- ✓ **Access to spirometry testing** needs to be given to all those at risk. As of the age of 35 years, smokers, former smokers and those with an occupational hazard need to undergo a lung function test, provided they present at least one respiratory symptom (dyspnoea, cough, wheeze, phlegm and/or recurrent respiratory infections).
- ✓ **Registration:** establish a register for COPD patients to support evidence based policy-making.

#### 2<sup>nd</sup> EFA COPD Workshop – Care and Research

The second EFA COPD workshop was held again at the European Parliament on November 9 and focused on care for COPD patients and research issues. The event was hosted by MEPs Sean Kelly and Karin Kadenbach. The workshop first heard from patient and employer representatives who explained how living actively and working with COPD is possible, but depends on adequate access to therapy and health systems which support patients' (and therefore also employers') real needs. The high cost of caring for patients who experience exacerbations was highlighted, and the importance of developing individualised patient strategies to reduce exacerbation rates was therefore stressed. A Finnish health representative then described how Finland has pioneered best practice in the field, and has succeeded in lowering COPD costs and improving care through a series of awareness raising

measures and better allocation of resources. More research on COPD issues was called for, particularly regarding the causes of exacerbations in patients and the under-explored link between COPD and depression and its resultant effects on patients.

It was unanimously stressed that awareness of COPD remains unacceptably low. EFA President Breda Flood said she hopes that the conclusions of the two workshops will prompt concrete action in the European Parliament, specifically an 'own-initiative report' urging the European Commission to take action. The EU Polish Presidency and the European Commission representatives shared their view on COPD.

Launch of the results coincided with World COPD Day WCD 16 November in our 2<sup>nd</sup> EFA COPD Project Newsletter<sup>9</sup>. The results – policy recommendations for Europe<sup>10</sup> - of the two workshops were communicated through EFA WCD press release<sup>11</sup> EFA called upon the EU and its member-states to implement the recommendations as soon as possible, to prevent, as it said 'an average estimate of 10 percent of Europeans from suffocating over the next decade.' [EFA COPD policy recommendations](#) It is hoped that the outcome of the workshops will initiate an "own initiative report by the European Parliament" on COPD by the European Parliament. This would be a high ranking recommendation urging national governments to address the needs of COPD patients across Europe. For the next year it is planned to continue to advocate for the own initiative report.

*MEP Karin Kadenbach, Polish Presidency Representative Agnieszka Czupryniak & Betty Sutton COPD Patient*



<sup>9</sup> <http://www.efanet.org/documents/EFANewsletterCOPDWorkshop2.pdf>

<sup>10</sup> [http://www.efanet.org/newsletter/lt/t\\_go.php?i=&e=%25subscriberid%25&l=http://www.efanet.org/documents/EFAWorldCOPDDayPressRelease\\_15November.pdf](http://www.efanet.org/newsletter/lt/t_go.php?i=&e=%25subscriberid%25&l=http://www.efanet.org/documents/EFAWorldCOPDDayPressRelease_15November.pdf)

<sup>11</sup> [http://www.efanet.org/documents/EFAWorldCOPDDayPressRelease\\_15November.pdf](http://www.efanet.org/documents/EFAWorldCOPDDayPressRelease_15November.pdf)

### Policy Recommendations – Care and Research of COPD

- ✓ **Disease Management:** With a view to preventing costly and irreversible exacerbations:
  - COPD care needs to become tailored to each patient's needs and support staying active, allowing patients to take ownership of the management of their disease;
  - the cooperation between specialists, primary care workers as well as those disciplines taking care of potential co-morbidities needs to be optimized;
  - healthcare workers need to adopt a more positive attitude towards smokers and COPD patients;
- ✓ **Access:** Throughout the EU, equal access needs to be given to oxygen and rehabilitation programmes. The formation of self-help groups needs to be promoted.
- ✓ **Best practice:** The EU needs to facilitate the dissemination of lessons learned from best practice programmes, such as the Finnish COPD programme.
- ✓ **Employment:** Employers need to be motivated to adopt flexible approaches to allow their staff with COPD to remain in the work force. Policymakers should promote such flexibility, as well.
- ✓ **Research:** With a view to achieving a sustainable improvement in the quality of life for COPD patients and ensuring their contribution to society, biomedical and health research must increase for COPD in the following fields:
  - How to reduce the risk of exacerbations;
  - How to improve the cooperation within a multidisciplinary team;
  - Real life studies to complement randomized controlled trials;
  - Co-morbidities, such as depression, and the interdependencies;
  - The impact of patient self-help groups.

## Collaboration and Partnerships

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EFA principle is that always collaborate with those who have a complementary perspective and expertise that we don't have. During the year the following were partner of our allergy or COPD projects, including primary and secondary care representatives: ARIA, ELF, ERS, GOLD, IPCRG. In addition, EFA now represents patients in four EU funded projects, with vast scientific and academia partnership.

### Understanding Allergy - Mechanisms in the development of allergy the MedALL project



EFA is delighted to be a partner in the MedALL project – Mechanisms of the Development of Allergy – a research project that is investigating the causes of allergy. MedALL is funded by the EU Research Programme, the FP7 and with 22 scientific partners plus EFA. The project results should help to provide better answers as to why and how allergy develops, and to design, clarify and target prevention opportunities and innovation in treatment. Patients have high hopes for the project.

Allergy often starts in childhood and it is children who are the focus of MedALL. Information from previous birth cohorts, including 42,000 children in Europe are looked at, and 18,000 re-examined using similar methods. MedALL's five year programme was kick-started on the 24th of January in Barcelona by the first MedALL Scientific Seminar summarizing what we currently know about different types of allergy/allergic diseases (IgE phenotypes) and what the gaps in knowledge are<sup>12</sup>. On the second and third day of the meeting the different work streams were organized.

EFA's role in the project is communication, dissemination and offering a patient perspective. EFA will keep its members informed and it is foreseen that training for patient representatives will be organized during the project. EFA will also help MedALL to contribute to EU policy. EFA promoted MedALL launch through press release<sup>13</sup>. <http://medall-fp7.eu/>

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<sup>12</sup> MedALL publications: [http://medall-fp7.eu/index.php?option=com\\_content&view=article&id=8&Itemid=6](http://medall-fp7.eu/index.php?option=com_content&view=article&id=8&Itemid=6)

<sup>13</sup> [http://www.efanet.org/newsletter/lt/t\\_go.php?i=&e=%25subscriberid%25&l=http://www.efanet.org/activities/documents/EFAMEdALLPressRelease.docx](http://www.efanet.org/newsletter/lt/t_go.php?i=&e=%25subscriberid%25&l=http://www.efanet.org/activities/documents/EFAMEdALLPressRelease.docx)  
Article on EC website  
[http://cordis.europa.eu/fetch?CALLER=EN\\_NEWS&ACTION=D&DOC=1&CAT=NEWS&QUERY=012ddb274cf:06a1:57469f0f&RCN=32992](http://cordis.europa.eu/fetch?CALLER=EN_NEWS&ACTION=D&DOC=1&CAT=NEWS&QUERY=012ddb274cf:06a1:57469f0f&RCN=32992)

## Personalized treatment for people with respiratory disease - Airway Disease Predicting Outcomes through Patient Specific Computational Modeling



On the 16th of September, the pan-European [AirPROM](#) project – in which EFA is partnering, and with the European Lung Foundation (ELF) co-leading on project dissemination to patients and public. AirPROM is a five-year EU- funded project, which aims to develop tools enabling personalized treatments for people with asthma and chronic obstructive pulmonary disease (COPD). Current methods of treatment adopt a ‘one size fits all’ approach rather than tailoring treatments to patient’s individual requirements. AIRPROM will help build up a bank of information that can be used to provide patients with a personalized treatment plan.

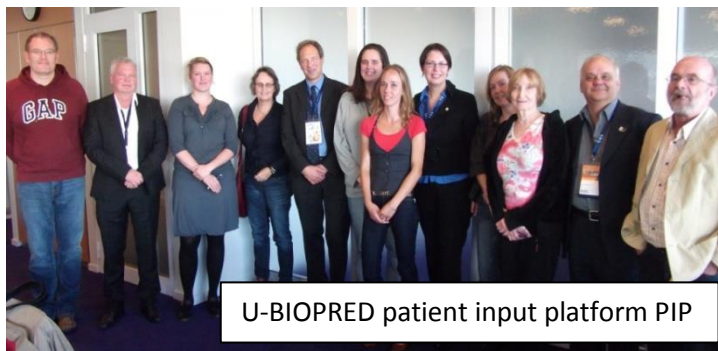
The project was launched on World Asthma Day and EFA sent out a press release<sup>14</sup>. The project website was launched in September together with a cartoon video<sup>15</sup> explaining what is done in this highly technical project. Over the course of the project, the researchers will use a number of techniques from image analysis, bioengineering, computation modeling and more, to develop virtual models of the whole airway system. These models will help to shed light on the optimum treatment that people with asthma or COPD should receive in order to live as normal a life as possible.

[www.airprom.eu](http://www.airprom.eu)

## Understanding severe asthma - Unbiased Biomarkers in the Prediction of Respiratory Disease



EFA attended the annual meeting of the [U-BIOPRED](#) project in Barcelona on the 17th and 18th of January. EFA is a partner in this project, which aims to understand more about severe asthma by gathering patients, scientists, and other stakeholders to collaborate in pioneering asthma research. The project has been underway for one year, and some significant targets have already been



met. With clinical trials of patients due to begin in the course of this year, the meeting also heard from patient representatives – the so-called U-BIOPRED Patient Input Platform – who offered their view on how best to ensure positive results.

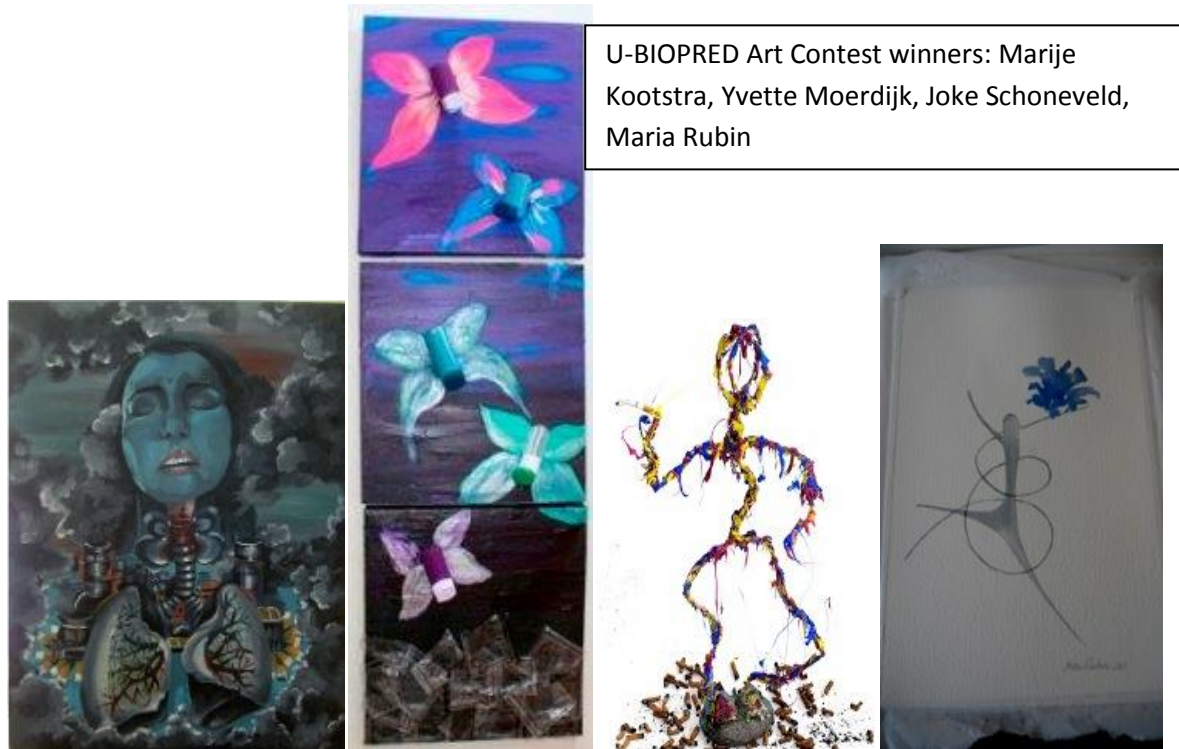
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[http://www.efanet.org/newsletter/lt/t\\_go.php?i=&e=%25subscriberid%25&l=http://www.efanet.org/enews/EFAReleaseVirtualLungModelsSettoPersonaliseAsthmaandCOPDCare.docx](http://www.efanet.org/newsletter/lt/t_go.php?i=&e=%25subscriberid%25&l=http://www.efanet.org/enews/EFAReleaseVirtualLungModelsSettoPersonaliseAsthmaandCOPDCare.docx)

15 <http://www.airprom.european-lung-foundation.org/16635-video.htm>



On World Asthma Day 3 May, EFA sent out a press release '[Art contest to show what life is like with asthma](#)'<sup>16</sup>. The winners came from Sweden and the Netherlands showing very different but equally effective ways to communicate patient perspective in severe asthma. The aim of the contest was to raise awareness and help promoting the U-BIOPRED as well a patient perspective on asthma within and outside the project.



<http://www.ubiopred.european-lung-foundation.org/>

### Indoor air quality – Health Based Ventilation Guidelines for Europe the HealthVent project



Health Vent project started in July 2010. The purpose of the project, funded by the EU Public Health Programme, is to develop health based ventilation guidelines for Europe that can be used as a policy making and practise tool by the EU member states. During the year EFA took part in the state-of-the-art review of existing knowledge on the topic from patient perspective, was involved in the development of the project website and hosted the project

consortium meeting in our offices in January. The guidelines will be available in late 2012.

[www.healthvent.eu](http://www.healthvent.eu)

<sup>16</sup>

[http://www.efanet.org/newsletter/lt/t\\_go.php?i=&e=%25subscriberid%25&l=http://www.efanet.org/news/EFAReleaseAsthmaartcontest.docx](http://www.efanet.org/newsletter/lt/t_go.php?i=&e=%25subscriberid%25&l=http://www.efanet.org/news/EFAReleaseAsthmaartcontest.docx)

## Acknowledgements for funders

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DG Health 5.000

### Sustainable industry partnerships

#### 5 Star\*\*\*\*\*

- GlaxoSmithKline - 55.000
- Novartis - 55.000

#### 3 Star\*\*\*

- ALK Abelló - 30.000
- Air Liquide Healthcare - 30.000
- AstraZeneca
- BoehringerIngelheim - 30.000
- Chiesi - 30.000
- Nycomed - 30.000
- Pfizer - 30.000
- Stallergenes - 30.000

### COPD Project

140.000 Air Liquide Healthcare, Astra Zeneca, Boehringer Ingelheim, GSK, Novartis, Nycomed, Pfizer. 20.000 each

### Allergy project

50.000 ALK Abelló, Stallergenes. 25.000 each